



Alström Syndrome UK

Strength for today, hope for the future

Alström Syndrome UK (ASUK) is a charity providing information, support and advice for individuals affected, their families, carers and professionals. Alström Syndrome (AS) is a very rare genetic condition which can cause progressive blindness, loss of hearing and can lead to; heart and kidney failure, type 2 diabetes, liver dysfunction and associated problems. The symptoms arise at different stages making diagnosis very difficult. Our mission is to raise awareness, conduct pioneering research and enable better treatments and monitoring through the AS multi-disciplinary NHS clinics. Further information about our work can be found at www.alstrom.org.uk

Welcome to the Winter 2022 ASUK Newsletter

Hello Everyone,

I hope you are well and looking forward to the festive period. Our winter newsletter is packed full of information and top tips, so I hope you enjoy catching up on everything that has been going on within the Alström Syndrome (AS) community.

I know things are not easy right now with the cost-of-living crisis. We have added some information on pages 4-9, so please have a read through and let us know if there is anything at all we can support you with. Our team are continuously looking for opportunities that the AS community can benefit from such as the SENSE Cost of Living grants and The Willow Foundation Treat Boxes. We have also been providing ASUK grants to support people through this crisis so please remember that we are here for you.

The Culture Sparkle Sisters continue to meet regularly and have provided some really useful top tips on page 11. It is so good to see how included the group feel within ASUK and recognise the importance of having their voices heard. We always welcome feedback and suggestions from you all.

The cold weather has certainly arrived and along with it comes illnesses. Please remember to keep your vaccinations up to date and seek medical advice if needed. I know that some children and young people have had to wait longer than usual for their clinic appointments due to issues with capacity in the service. We are continuing to work with the team at Birmingham Women's and Children's Hospital to try and offer some reassurance to families and an additional two virtual clinics have been added next year. Please let us know if you have any concerns.

On page 2 you will find an overview of the AS Global Conference which took place on Saturday 3rd December 2022. We were so pleased to have over 100 people register for the event from 24 different countries. The mix of talks from people with lived experience and medical and scientific updates from around the world kept the audience captivated throughout the whole day.

Next year, we celebrate our 25th anniversary and hope that you will join us to mark this milestone in ASUK's history. ASUK was incorporated on the 1st May 1998 and together, we have come such a long way. We will be celebrating throughout the year so there will be lots of opportunities to get involved. We will be sharing our ideas with you all in January and hope that you can share some suggestions with us too, for ways that we can come together and celebrate as a community.

As I reflect on 2022, I have mixed feelings. It has been a challenging year as the world seems to move from one crisis to another and we have experienced the sad loss of some of our treasured and much-loved friends. We also have so much to be thankful for and I end the year with a sense of hope. The AS medical and scientific community within the UK and beyond are really starting to work together and push forward with research. I know these things take time and as a Mum, I share some of your frustrations about the fact that we do not yet have a specific treatment for Alström Syndrome. I do believe that there is hope and by working together, we will continue to improve our knowledge of the condition which in time, will lead to better and more effective treatments. On behalf of the team at ASUK, I would like to say a huge thank you to all the clinicians, researchers, and scientists, we are very grateful for everything they do.

I would also like to say a very big thank you to all our friends, families and supporters who have given so generously to ASUK throughout the year. A very special thank you to Jane Young and The Sylvia Adams Charitable Trust for all their support for the Breaking Down Barriers project. Please see our special tribute to them on page 10.

We hope you all enjoy the festive period and wish you health and happiness for 2023!

Take care everyone.

***We are here for you
Kerry and the ASUK team***



The Global Conference Report will be published in the new year, meanwhile here's a brief snapshot

Thank you to everyone!

Don't worry if you missed any session – all presentations from the Conference will be uploaded onto the ASUK website in the New Year.

In true virtual style, with over **100 registrations**... the Alström community came together; to learn from one another and share their stories at the AS Global conference. This year it was bigger than ever with families and professionals from **24 Countries** joining online.

On Saturday 3rd December 2022, presenters from Germany, Italy, the UK, and America shared their knowledge and experience.

The aim was not only to bring the community together but provide a global insight through presentations from families, researchers, and clinicians from around the world.

We know that having an ultra-rare condition like Alström Syndrome can sometimes be a lonely place; feeling that no one really knows what you are going through. The global conference is an opportunity to talk and learn together. It shows us all the strength and resilience throughout the community and to support each other.

The first sessions of the day, centred around a Dad's ambition to provide support and research opportunities in Germany. **Bernd** shared his story of how his son Ben, creates artwork that is inspiring others to follow their dreams.

Prof. Pietro Maffei Consultant Endocrinologist from Padua University in Italy was up next with his popular session 'Live Life on the Med!' All about the benefits of following a Mediterranean diet. Pietro shared his top tips of how discovering the delicious food of the Mediterranean can help keep you healthy.

Next, we welcomed **Professor Rick Steeds**, Consultant Cardiologist and Deputy Director of Clinical Research, Queen Elizabeth Hospital, Birmingham and the Chair of the AS Medical and Scientific Advisory Group. Rick took us on a worldwide tour of the research happening across Europe.

This was followed by **Professor Rob Semple**, Chair of Translational Molecular Medicine at the Centre of Cardiovascular Science, University of Edinburgh and **Eleanor McKay**, PhD student in Cardiovascular Science. They gave an overview of their research into the role that unhealthy fat tissue plays in diabetes, heart and liver problems that are often seen in people affected by AS.

Jonathan Eintracht, PhD student from Great Ormond Street Hospital, gave an exciting overview of the development in eye research and how this may benefit people with AS in the future.

The next three talks shared some insights on living with Alström

First to present was **Melissa (ASUK Trustee) and Alisha** with their presentation called 'Don't wrap me in cotton wool!' –



looking at a young person's experience of Alström Syndrome. Alisha's gave some top tips for Moms, Dads, and all...

Then we heard from **Dr Richard Paisey** who explored the evidence behind why exercise is vitally important to keeping fit and healthy with AS. Richard, was joined by our very own Trevor (Advisor to the Board of ASUK) who shared his experience of using a fitness tracker and how this has motivated him to exercise more.

Next, we heard from **Hassan**, sharing his story about riding his tandem to trek across Europe. Hassan was joined by his Dad, **Kez** who shared his insights into how difficult it can be to let go as your child grows into an adult, but how it can be positive for the whole family if this can be done in a supportive way.

We were delighted to welcome **Chase Palmer** from Alström Syndrome International, **Marina Valenti** from ASSAI in Italy, **Bernd Rosenbichlet** from AS Germany, and our very own **Kerry Leeson-Beevers** from ASUK to share their updates on what is happening in their corner of the world.

Lastly, **Ann Chivers** (Executive Director, AS Global) thanked all of the presenters and emphasised the commitment of AS Societies and Groups around the world to work and learn together to further research and support services for all those affected by Alström Syndrome.

Kerry and Ann shared the exciting news that ASUK will be having a silver anniversary year. ASUK will be 25 years old next year!! – it is going to be a year of get togethers and celebrations starting with a family gathering in the UK in April.



Join in!

We are launching the 'Rare Moments' Art Exhibition

You are all invited to grab your camera, paint brushes, crayons, plasticine, clay, collage or any other medium you choose and create your 'Rare Moments'

We will be developing an online exhibition all about Alström Syndrome net year!

Take 25!

Maybe you would prefer to do something more active... Challenge yourself to do 'Take 25' – 25 push-ups, run 25 miles or jump 25 star jumps!! The world is your oyster!!

We will be exploring more about this in the up-and-coming global webinar on
Thursday 26th January 2023 from 7:00 – 8:00 pm (UK, GMT)

Everyone is welcome.



Rare Moments!

Let's Celebrate 25 years of Alström Syndrome UK

Do you think of yourself as the next Picasso or David Bailey?

Calling all individuals, family members and professionals...

Grab your camera, paint brushes or tactile art products and send us your 'Rare Moments'



Send your creations to Catherine at
catherine.lewis@alstrom.org.uk or post to:
4 St Kitts Close, Torquay, Devon TQ2 7GD ENGLAND
By the 31st March 2023 to be part of the
Rare Moments Exhibition!

www.alstrom.org.uk/asuk-turns-25/



NHS Alström Syndrome Multi-Disciplinary Clinics

Birmingham Women's and Children's Hospital clinic dates for 2023:

30th January
8th March (virtual/telemedicine)
24th April
10th July
27th September (virtual/telemedicine)
9th October

Queen Elizabeth Hospital, Birmingham adult clinic dates for 2023:

18th and 19th January
15th and 16th March
17th and 18th May
14th and 15th June
20th and 21st September
15th and 16th November

Outreach Clinic in Leeds in November - date to be confirmed

Cost of Living Crisis!

We hope you are well and coping with the continued financial and emotional strain that the cost-of-living crisis is having on the Country right now.

We know that as we embark on winter, many of us will find these times even more challenging. Often the hardest thing to do is to put our hand up and say, 'yes I am struggling and need support'. During these unprecedented times, it is only by doing this that we can find ways to really help and support you.

Families around the Country are having to make difficult decisions like 'heating or eating' and this just isn't right.

We were pleased to work with the charity SENSE to help distribute some of their 'cost of living' funds to families who met the eligibility criteria within ASUK. We are continuing to look for similar opportunities to help all individuals and families where we can. This may be in the way of financial assistance or providing equipment such as air fryers, warm clothes and blankets.

What we need from you, is to please let us know if you are struggling at this time. We just need a few words in an email or text and a quick chat to understand how this is impacting you and what support would be most helpful to make a difference to you and your family.

Our Care Coordinator, Sarah works Monday to Thursday and would love to hear from you.

You can contact her on sarah.oliver@alstrom.org.uk or give her a call or text on 07917 958502.

Our family support team are only a phone call, text or email away. Also, if you need to review your benefits or just want someone to talk to, please get in touch.

All information you provide will as always be kept in the strictest of confidence.

We have provided some information below about services which may be able to help you at this difficult time.

Join your energy supplier's Priority Services Register

If you live in England, Scotland or Wales, we would strongly advise you to contact your energy supplier to register as a vulnerable customer on their Priority Services Register.

What does being on the Priority Services Register do?

Being on your energy supplier's Priority Services Register means they know you are a vulnerable customer.

Many suppliers will give vulnerable customers advanced notice of planned power cuts and offer priority support during emergencies. Some may be able to provide cooking facilities, hot meals or charge points to households that rely on medical equipment.

Alongside providing extra support as a vulnerable customer, suppliers must take all reasonable steps to avoid disconnecting you during the winter months (1 October – 31 March). Suppliers that have signed up to Energy UK's Vulnerability

Commitment cannot knowingly disconnect a vulnerable customer at any time of the year.

You can also join the register of your energy network operator. This is the company that provides the pipes and cables that bring energy from your supplier to your home.

How do I register?

Contact your energy supplier and ask them to put you on their Priority Services Register.

Government support for cost of living

The UK government has announced various measures to help families with rising energy costs and other cost of living increases.

Cost of living support payments

£650 for low-income families

Low-income households on most means-tested benefits or tax credits will receive £650.

To be eligible, you must be on one of the following benefits:

- Universal Credit.
- Income Support.
- Income-based Job Seekers Allowance.
- Income-related Employment and Support Allowance.
- Child Tax Credit or Working Tax Credit.
- Pension Credit.

It does not apply to those who only get Housing Benefit and/or a council tax reduction.

The government is paying these in two lump sums of £326 and £324. There's no need to apply, as eligible claimants will receive both instalments automatically.

Most of the first payments of £326 were paid between 14 July and the end of July 2022. The second instalment of £324 should have been made by the end of November 2022.

However, families who get Working Tax Credit or Child Tax Credit will only receive their first instalment in the autumn and their second payment in winter.

These instalments are not taxable and won't affect the benefits or tax credits you receive.

For more information on who is eligible for this one-off payment, visit the government's website <https://www.gov.uk/guidance/cost-of-living-payment>.

Missing your payment?

If you think you're missing your payment, you can report this on the Department for Work and Pensions (DWP) website <https://secure.dwp.gov.uk/report-a-missing-cost-of-living-payment/welcome>.

£150 for those on disability benefits

Individuals who receive a qualifying disability benefit, such as Disability Living Allowance or Personal Independence Payment (or Child Disability Payment or Adult Disability Payment in Scotland), are eligible for a one-off sum of £150.

To be eligible, you must be in receipt of (or have begun an eventually successful claim for) one of the qualifying disability benefits as of 25 May 2022.

The government began making these payments on 20 September 2022. The vast majority should have received their payment by now. The process may take longer for those who were awaiting confirmation of their disability benefit on 25 May 2022.

Those who are eligible for the low-income payment and the disability payment will receive both sums. This amounts to a total of £800.

£400 discount for all households with electricity supply

Households with a domestic electricity supply are eligible for a £400 discount to help them with their energy bills.

Northern Ireland introduced the scheme at a later date than the rest of the UK.

Families in England, Scotland and Wales

You'll receive the £400 in six separate instalments of £66 or £67. The payments will arrive between October 2022 and March 2023.

You will get the discount automatically from your electricity supplier if either:

- You pay your electricity bill by direct debit.
- You pay your bill by standard credit. (This means you pay by cash, cheque or card after receiving a bill by post).
- You have a smart prepayment meter.

Depending on your supplier and how you pay, this will be done by crediting your electricity account or a refund directly into your bank account.

If you have a traditional (non-smart) pre-payment meter, it's a bit more complicated. You will receive six separate vouchers via text, email or post. You'll need to redeem these by topping up as usual in a shop or post office. You will have three months to redeem these vouchers, and you could lose out if you delay in redeeming them.

If you pay for your electricity as part of your rent to your landlord, the government has said that it expects landlords that resell electricity to their tenants to "pass the discounted payments on appropriately".

Warning: In all cases, no one should ask you for bank details at any point. Stay alert for potential scams and report anything you suspect to the relevant authorities.

You will receive this £400 discount on top of any other help with fuel costs that you qualify for. This includes the Warm Home Discount scheme, Child Winter Heating Assistance in Scotland, or the Winter Fuel Support Scheme in Wales.

For more information on the discount, take a look at the government's factsheet on their website <https://www.gov.uk/government/publications/cost-of-living-support/cost-of-living-support-factsheet-26-may-2022>.

Families in Northern Ireland

The Northern Ireland Executive (NIE) Finance Minister, Conor Murphy, confirmed on 26 August that the UK Government will deliver the £400 Energy Bill Support Scheme to people living in Northern Ireland.

This is expected to start at a later date than in other parts of the UK. At the moment, payment details are unknown.

£150 Council Tax bills rebate (England, Scotland and Wales)

In England, Wales and Scotland, households in Bands A-D received a £150 rebate in Council Tax bills.

You do not need to repay this.

£300 pensioner cost of living allowance

This is for pensioner households (those where a person is 66 or over between 19-25 September 2022) as a top-up to their annual winter fuel payment in November/December 2022.

Discretionary grants from your local council

If you are on a low income and you're struggling financially, it's worth applying to your local authority to see if you can access any grants, loans or assistance in kind. For more details, see the charity, Contact's webpage about grants, loans and local welfare schemes <https://contact.org.uk/help-for-families/information-advice-services/money-debt/grants-loans-welfare-schemes/#local-welfare-assistance-schemes>.

Support from April 2023

In the Autumn Statement in November 2022, Chancellor Jeremy Hunt announced the following cost of living payments from April 2023:

- £900 for those on means-tested benefits.
- An additional £300 payment for pensioners
- Another £150 disability cost of living payment for those on disability benefits, such as DLA and PIP.

The Energy Price Guarantee, which caps the price of the average domestic energy bill on the variable rate, will be extended for a further 12 months from April 2023. But it will become less generous, with the average bill in 2023/24 being capped at £3,000, rather than the current £2,500.

The government will also make £1 billion available to local authorities as part of the Household Support Fund. This allows councils to deliver support with the costs of essentials in their areas.

Help with household bills

There are several schemes and grants to help you with water, fuel and other utility bills. Find out whether you're eligible and how to apply.

The Warm Home Discount Scheme

Under this scheme, you can receive a rebate worth up to £150. This does not come to you. Instead, it is deducted from your winter fuel bill. The scheme applies in England and Wales, and it operates in Scotland but differently.

You will qualify if your energy provider is part of the scheme and either:

- You're a pensioner who receives the guaranteed credit of Pension Credit.
- You fall into 'core group two' (known as the broader group in Scotland): people on lower incomes who are likely to have higher energy bills.

For you to be eligible to claim, you or your partner's name must be on your energy bills and your supplier must take part in the scheme. The gov.uk website lists all the firms that currently participate <https://www.gov.uk/the-warm-home-discount-scheme>.

Do I fall into core group two/the broader group?

England and Wales

You are eligible under core group two if you are in receipt of a qualifying means-tested benefit **and** you have high energy bills.

The list of qualifying means-tested benefits are:

- Income related Employment and Support Allowance.
- Income based Jobseeker's Allowance.
- Income Support.
- Housing Benefit.
- Universal Credit.
- Child Tax Credit (with an income below certain levels).
- Working Tax Credit (with an income below certain levels).

You must also be assessed as someone likely to face higher energy bills than other households.

You can check whether you're eligible by using the Government's online eligibility checker on their website <https://www.check-warm-home-discount-eligibility.service.gov.uk/contacted-by-beis/>.

There are major changes to the broader group for winter 2022. For the first time, families in England and Wales who qualify are guaranteed a payment, rather than it being a "first come, first served" system.

Scotland

In Scotland, you fall into the broader group if you are on one of the qualifying disability benefits and either:

- You have a child under five.
- Your means-tested benefit includes a disabled child element/ disabled child addition or extra amounts for a disabled adult.

Who else might be eligible?

Suppliers also have the discretion to apply more generous rules offering discounts to other groups on a low income. To find out if your supplier is taking part in the scheme, visit the government's Warm Home Discount Scheme webpage <https://www.gov.uk/the-warm-home-discount-scheme>.

Receiving a payment if you're eligible

In England and Wales

You will receive a letter by mid-January 2023 telling you that you receive the payment automatically and that you don't need to do anything. Alternatively, you might receive a letter telling you to call a dedicated helpline to provide further evidence. This is so the government can decide whether or not you qualify. Energy suppliers will make payments automatically by March 2023.

In Scotland

You are not paid automatically. Instead, you need to apply to your energy provider. You should do this as soon as possible. The number of payments available to the broader group in Scotland are limited and generally made on a 'first come, first served' basis.

Child Winter Heating Assistance (Scotland only)

This is a £202 payment from Social Security Scotland to help towards your winter heating bill. You qualify if you live in Scotland and have a child aged under 18 entitled to the highest care component of Disability Living Allowance (DLA)/Child Disability Payment or the enhanced daily living component of Personal Independence Payment.

The payment is for each child who qualifies. So, if for example you have two children who are both on the higher rate care component, you should receive £400. The scheme is not means-tested, so it makes no difference what income or capital you have. In order to qualify for a payment in winter 2022/3, a child must have been entitled to one of the benefits mentioned above at some point in the week beginning 20 September 2021.

For more information, see the charity, Contacts webpage on Welfare Benefits in Scotland <https://contact.org.uk/help-for-families/information-advice-services/benefits-financial-help/welfare-benefits-in-scotland/>.

Winter Fuel Support Scheme (Wales only)

During Winter 2022, the Welsh Government will provide a one-off £200 payment to families in Wales who receive certain benefits. This includes households receiving means-tested benefits such as Universal Credit, Income Support or Housing Benefit and families on tax credits. You are also eligible if you are the person responsible for the fuel bills and you receive a carer's or disability benefits. This includes Carer's Allowance, Disability Living Allowance or Personal Independence Payment. You can apply for this scheme via your local authority.



Cold weather payments (England, Wales and Northern Ireland)

You may qualify for cold weather payments if you experience a period of very cold weather in your area. You will qualify if you are on an income-related benefit, such as:

- Pension Credit.
- Income Support.
- Income-based Jobseeker's Allowance (JSA).
- Income-related Employment and Support Allowance (ESA).
- Universal Credit, but only if you are not working.
- Support for Mortgage Interest.

and you have any of the following:

- A child under five in your family.
- A child for whom you get an extra disabled child element or addition as part of your tax credits or Universal credit award.

or you receive:

- An extra amount for your own disability or for being over state pension age and you don't live in a care home.

If the average temperature recorded or forecast over seven days in a row in your local area is zero degrees Celsius (freezing) or less, you will receive an automatic payment of £25. You do not have to do anything to receive the payment. Use the government's Cold Weather Payment tool to find out if your area is due to receive a payment

<https://coldweatherpayments.dwp.gov.uk/>.

Winter Heating Payment (Scotland only)

Cold weather payments do not apply in Scotland. Instead, families in Scotland on certain means tested benefits will automatically receive an annual payment of £50. Payments for winter 2022 will start from February 2023.

To qualify you must have been in receipt of one of the following benefits during the 7 Nov to 13 Nov:

- Universal Credit.
- Pension Credit.
- Income Support.
- Income based Jobseeker's Allowance.

Do you know hot water bottles go out of date?

If you've ever seen the flower-shaped symbol on your hot water bottle, you might have thought it was just there for decoration. But it has an important safety meaning.

What does the flower on hot water bottles mean?

The flower symbol on hot water bottles indicates when they were made. In the centre of the flower is a date indicating the year - so, 22 for those made in 2022 - and 12 petals indicating the month the hot water bottle was manufactured.

If your hot water bottle is more than three years old, experts say it's time to get a new one. This is because older water bottles may be at greater risk of bursting open, which can leave people with serious scalding.

- Income Related Employment Support Allowance.
- Support for Mortgage Interest.

In addition, your means tested benefit must include at least one characteristic from a list of features. This includes where it includes an extra payment known as the disabled child premium or disabled child addition. For the full list of criteria see <https://www.mygov.scot/winter-heating-payment/who-is-eligible-for-winter-heating-payment>

Energy supplier hardship grants

Some energy suppliers offer grants to help households struggling to pay their energy bills. Visit Citizens Advice for an updated list of supplier schemes

<https://www.citizensadvice.org.uk/consumer/energy/energy-supply/get-help-paying-your-bills/grants-and-benefits-to-help-you-pay-your-energy-bills/>

If your energy supplier does not offer grants, you may still be eligible for support from the British Gas Energy Support Fund. Visit the British Gas Energy Support Fund website for a list of available grants <https://britishgasenergytrust.org.uk/grants-available/>.

Change how you pay

Contact your energy supplier to talk about different ways that you can pay your bill. Some suppliers will give a discount if you pay by a particular method.

Think about using payment plans that spread the cost, which can help you avoid arrears. Take care to check the terms and conditions of each payment plan.

If you are on:

- Universal Credit.
- Income Support.
- Income-based Jobseeker's Allowance.
- Income-related Employment and Support Allowance (ESA).
- Pension Credit.

You may be able to pay for your current fuel usage through your benefits. This is known as fuel direct. To set up fuel direct, contact Job-Centre Plus or your pension centre if you receive pension credit.

How long do hot water bottles last?

Quality hot water bottles typically last two or three years, although some hot water bottles may need replacing much sooner than this. If your hot water bottle is more than three years old, it's best to replace it with a new one.

You should not wait until your hot water bottle leaks before buying a replacement. Always check your bottle for signs of wear - including splits and leaks - each time before you use it.

Hot water bottles are susceptible to wear and tear over time. Older hot water bottles are more susceptible to splits, which can cause users serious injury and leave them with painful burns.



Keeping an eye on your bills

- Many suppliers offer schemes to help with costs, such as making your home more energy efficient. Reduced tariffs are increasingly hard to find amid an energy price crisis in 2022.
- Your bill might be based on estimate readings. Check your bill against your meter and if the readings are different ask for an amended bill.
- Make sure you check any scheme you sign up to doesn't lock you in for a long time or incur penalties for leaving.
- Consider switching suppliers; see OFGEM's website for advice. (Note: many energy companies are closing amid an energy price crisis in 2022, so at the moment you may find that your current rate is the best available. Do your research first.) <https://www.ofgem.gov.uk/information-consumers/energy-advice-households/switching-energy-tariff-or-supplier>.

Tips to save on heating and fuel costs

- Turning down your thermostat by just 1°C can cut your fuel bills by up to 10 per cent, saving you about £70 a year.
- You might be able to make savings by using a different type of meter. For example, prepayment meters allow you to pay in advance for your fuel usage.
- Set the heating to come on 15-30 minutes before you need it and to go off 30 minutes before you leave the house.
- Turn radiators off in rooms you're not using, keep furniture away from radiators and use radiator panels to reflect heat back into the room.
- Use draft excluders and draft proofing tape around windows, doors, letter boxes and keyholes. You could save £50 a year just by draft proofing.
- Zipping up your hot water cylinder with a 75mm lagging jacket could save you £35 per year but cost just £10.
- Shutting the curtains will stop heat escaping through your windows and doors after dark, but don't pull them over radiators or you'll lose heat.

Tips to save on water costs

Water meters let you pay for your water in advance. Visit the Citizens Advice page on water meters to find out if a water meter could help you <https://www.citizensadvice.org.uk/consumer/water/water-supply/paying-your-water-bill/changing-to-a-water-meter/>.

- You are entitled to a free water meter installation from your water company, providing it isn't impractical or unreasonably expensive.
- If you have a shower, encourage your family to shower rather than have a bath; a five-minute shower uses about 30 per cent less water.
- Take a close look at your cylinder thermostat – there's no need for it to be set higher than 60°C/140°F.

Tips to save on electricity and appliance costs

- By switching off lights in empty rooms and corridors, you can save up to 15 per cent on your bill.
- Keep a lid on your cooking. Use just enough water to cover food or use a steamer. Boil cooking water in the kettle not the saucepan.
- Cooking smaller pieces of food is quicker and cheaper.
- Washing at 30°C uses 40 per cent less electricity than higher temperatures. Try as much as you can to wash at 30°C and to wash full loads.

- Next time you replace an appliance, look for cheaper, more efficient 'A' rated devices. Appliances account for about 47 per cent of energy bills.
- Appliances can use energy when on standby, so get into the habit of turning them off. An average household can save £30-£40 a year just by doing this.

Get involved...it's a family affair

Get the whole family involved in thinking about ways to save energy; they'll become very energy conscious and may well think of something we haven't.

To find out more about energy efficiency visit www.gov.uk/energy-grants-calculator or phone the Energy Saving Advice Service on 0300 123 1234 / Home Energy Scotland on 0808 808 2282.

There's really useful advice in the Keep Warm Keep Well booklet produced by the Government. This booklet aims to help you maintain good health during winter and take advantage of the financial help and benefits available. It is aimed at over 60s, low-income families, and people living with a disability <https://www.gov.uk/government/publications/keep-warm-keep-well-leaflet-gives-advice-on-staying-healthy-in-cold-weather>

Saving money on your energy bills

Understanding your energy usage and charges is a good starting point for reducing your energy costs, if you pay for your energy via credit this information can be found in your energy bill.

Your energy bill will include a breakdown of costs, such as daily standing charges and the cost of energy used in the period covered by the bill, tariff information and a record of your past energy usage.

The Energy Saving Trust has a useful guide on understanding your energy bill <https://energysavingtrust.org.uk/how-to-understand-your-energy-bill/>.

There are also lots of free or low-cost ways to save money on your energy bills. Phone the Energy Saving Advice Service on 0300 123 1234 / Home Energy Scotland on 0808 808 2282.

Stay safe with fires, heaters, and electric blankets

In severe weather, you may be making use of fires and candles for warmth, ambience, or in the event of power cuts, for light.

To stay safe using fire, you are advised to ensure that you have a smoke alarm on every level of your home and that you test it regularly.

You should also do the following:

Open fires: sweep your chimney, use a fireguard, make sure the fire is put out properly before you leave the room.

Electric heaters: keep away from curtains and furniture, and do not use for drying clothes. Always unplug when you go out or go to bed.

Electric blankets: do not use a hot water bottle, even if the blanket's switched off. Unplug blankets before you go to bed unless they have thermostat control for safe all-night use.



Where can I find further information?

Citizens Advice have brought together a variety of resources to check if you are eligible for a range of benefits and financial support through the cost-of-living crisis:

<https://www.citizensadvice.org.uk/debt-and-money/get-help-with-the-cost-of-living/>

The charity Contact, for families with disabled children has an area on their website offering advice on the cost of living crisis:

<https://contact.org.uk/help-for-families/information-advice-services/cost-of-living-advice/>

The Government have developed a factsheet 'Overall Government support for the cost of living':

<https://www.gov.uk/government/publications/government-support-for-the-cost-of-living-factsheet/government-support-for-the-cost-of-living-factsheet>

Always remember we are only ever a phone call or email away!

Protect Yourself this Winter

Flu occurs every year, usually in the winter, which is why it's sometimes called seasonal flu. It's a highly infectious disease with symptoms that come on very quickly. Colds are much less serious and usually start gradually with a stuffy or runny nose and a sore throat. A bad bout of flu can be much worse than a heavy cold.

The most common symptoms of flu are fever, chills, headache, aches and pains in the joints and muscles, and extreme tiredness. Healthy individuals usually recover within 2 to 7 days, but for some the disease can lead to hospitalisation, permanent disability or even death.

Flu is unpredictable and the flu vaccination provides the best protection. There are different strains of flu virus. The strains that are most likely to cause illness are identified in advance of the flu season. Vaccines are then made to match them as closely as possible. Even if the vaccine doesn't perfectly match a strain, it usually provides some protection against it. The vaccines are given in the autumn ideally before flu starts circulating.

If you had the flu vaccination last year – you need another one this year

The flu viruses can change from one winter to the next. Flu vaccines are updated for each winter to give protection against the strains of flu that are most likely to be going around. For this reason, we strongly recommend that even if you were vaccinated last year, you should be vaccinated again this year.

Also, protection from flu vaccination goes down with time so even if some of the strains are the same you should have a flu vaccine again each flu season.

The harm flu can do

People sometimes think a bad cold is flu but having flu can often be much worse than a cold and you may need to stay in bed for a few days. In the worst cases, flu can result in a stay in hospital, or even death.

Some people are more susceptible to the effects of flu. For them, it can increase the risk of developing more serious illnesses such as bronchitis and pneumonia or can make existing conditions worse.

Flu can affect anyone but if you have a long-term health condition the effects of flu can make it worse even if the condition is well managed and you normally feel well.



The children being offered the vaccine this year, are:

- ♥ all 2 and 3 years of age on 31 August
- ♥ all primary school-aged children
- ♥ some secondary school-aged children

Children aged 2 and 3 years will be given the vaccination at their general practice, usually by the

practice nurse. School aged children will be offered a flu vaccine in school or can be vaccinated at community clinics. For most children, the vaccine will be given as a spray in each nostril. This is a very quick and painless procedure.

For more information on children and flu vaccination, visit NHS.UK <https://www.nhs.uk/conditions/vaccinations/child-flu-vaccine/>

The types of flu vaccine available

There are several types of flu vaccine. You will be offered one that is most appropriate for you. Most children are offered the vaccine as a nasal spray and adults are offered an injectable vaccine. None of the vaccines can give you flu.

If your child is aged between 6 months and 2 years old and is in a high-risk group for flu, they will be offered an injected flu vaccine as the nasal spray is not licensed for children under the age of 2 years old. Some children over the age of 2 years who are in a high-risk group will also need to have an injected vaccine if the nasal spray vaccine is not suitable for them.

The nasal vaccine contains gelatine derived from pigs (porcine gelatine)

The nasal vaccine contains a highly processed form of gelatine (porcine gelatine), which is used in a range of many essential medicines. The gelatine helps to keep the vaccine viruses stable so that the vaccine provides the best protection against flu.

The nasal vaccine is offered to children as it is more effective in the programme than the injected vaccine. This is because it is easier to administer, may offer better protection than injected vaccines and is considered better at reducing the spread of flu. However, if your child is at high risk from flu due to one or more medical conditions or treatments and can't have the nasal flu vaccine, they should have the flu vaccine by injection.

For those who may not accept the use of porcine gelatine in medical products, an alternative injectable vaccine is available. You should discuss your options with your nurse or doctor, or school aged immunisation service.

Alström Research Developments

On the 28th October 2022, AS patient organisation representatives, scientists and healthcare professionals from across Europe met in Tübingen in Germany (pictured below). The meeting was to discuss European research and clinical developments and ways to collaborate effectively going forward. This meeting was a great opportunity to meet in person, which hasn't happened due to Covid-19 for such a long time. We would like to thank Bernd from the AS Initiative in Germany for organising this meeting and we look forward to continuing to work together.



On the 2nd December 2022, we held our 2nd AS Medical & Scientific Advisory Group meeting of the year in the UK. ASUK coordinates these meetings and brings together patient representatives, clinicians and researchers from around the UK with an interest in AS. We discuss current research projects, future possibilities, collaborations and funding opportunities. It is encouraging to see the amount of research that is ongoing in the research labs and through the multi-disciplinary clinics. We will be organising a Global Medical & Scientific meeting later in 2023 where we plan to share our findings and invite others from around the world to join us so that we can learn from one another.

Breaking Down Barriers, start of a new chapter!

With funding and support from The Sylvia Adams Charitable Trust, ASUK started championing Equity, Diversity and Inclusion from 2008 and in 2016, we founded the Breaking Down Barriers project. We help develop and facilitate a network of organisations working together to increase engagement and involvement with people from diverse and marginalised communities who are affected by rare and genetic conditions. Striving for equitable access to healthcare, services and support is at the heart of everything we do.

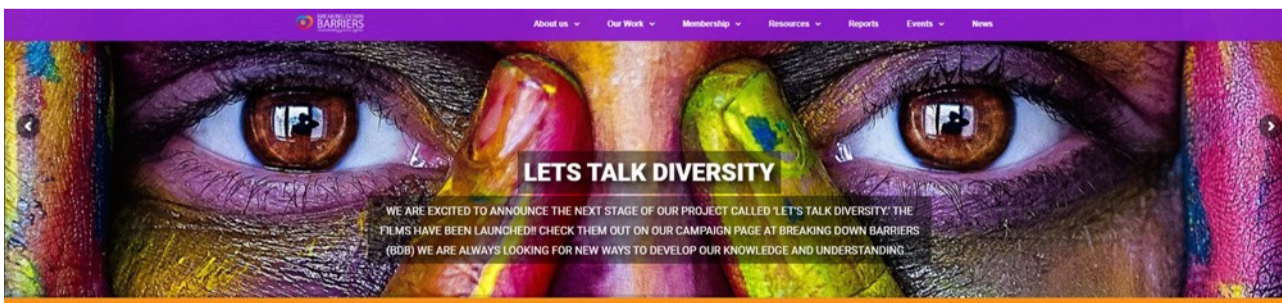


The Sylvia Adams Charitable Trust

The BDB project now has **over 60 member organisations** and the reach and creative ambitions from the team are going from strength to strength.

All this development has been possible due to the generous funding and support we have received from The Sylvia Adams Charitable Trust. The Trust is a time limited organisation and is closing from December 2022, ending 27 years of grant making and the distribution of nearly £20 million to a wide range of global charities! They have left us in a strong position to continue this work and we are also looking to bring new funders on board.

We are incredibly grateful to the Sylvia Adams Charitable Trust for their continuous support over the years, and in particular, to their Director, Jane Young (pictured right on the left hand side with Kerry), who has been by our side every step along the way.



Breaking Down Barriers SINCE 2008 Championing Equity, Diversity and Inclusion

We are a network of over 60 organisations working together to improve the lives of families from diverse and marginalised communities, who are affected by genetic conditions so they have equal access to health services.

There is no such thing as hard to reach communities, only services and organisations that can be difficult for people from diverse communities to access.

Addressing health inequalities is at the centre of what we do: finding



The BDB website has had a make over, check it out at

www.breaking-down-barriers.org.uk

Culture Sparkle Sisters - Together we are stronger! Our voices are getting louder! 2023 brings new voices and a new inclusive name!

The Culture Sparkle Sisters (CSS) continue to go from strength-to-strength meeting monthly to discuss a number of topics. This year they welcomed a new member to the group, who brings lots of enthusiasm and ideas to the meetings. *'It's really fun talking to all the CSS!' Aisha.* The topics that the CSS discuss are vast and varied with lived experience being shared by all the members. They also have guest speakers talking about topics such as, what's it like to have a personal assistant? or what do habilitation workers do to help you? Sharing top tips is an important part of the discussions, as the CSS continue to learn from each other.

To kick off 2022 the CSS interviewed ASUK Chief Executive, Kerry Leeson Beevers, who had recently taken up the position. Kerry shared how varied day to day role, including talking to families, adults, children, and young people to help steer the direction of ASUK. Kerry works with the Trustees to manage the ASUK budget and funding that ASUK needs to run properly. Kerry also has many discussions with health professionals, clinicians and scientists around the world. This focuses on research and learning more about Alström Syndrome (AS) to improve people's quality of life and seek further treatments.

In March 2022 the CSS invited an ASUK Trustees, Alex to talk about, 'what is it like to have a personal assistant (PA)?' A PA can support you to go out in the community, do things with you in your home and increase your independence. You need an assessment by a Social Worker to qualify for a PA. The CSS also shared their experience and views of PA's.

Top Tips for having a PA

- When you do things with your PA you get to know each other, you start to have fun together. You become friends, be honest with them about what you need help with - Alisha
- Talk to your PA and tell them what you like to do - Katie and Hannah
- Make sure you are comfortable with your PA, learn to trust them and find out the things that you both like/have in common - Alex
- It's good to know how a PA can help, when someone is ready to have a PA to support their life – Samah

Melissa who is one of the CSS facilitators is also part of the AS Global Team. She helps to bring together individuals affected by AS, clinicians and researchers from around the globe. Melissa asked the CSS to come up with top tips to share with parents, carers and professionals to support new families diagnosed with AS.

Top tips to help newly diagnosed children or young people (CYP)

- Tell CYP about Alström when a parent or carer thinks they can understand some things about it
- If the CYP are seeing lots of doctors, they should know why they are seeing them
- If the CYP are asking questions, tell them the answers and be honest! You can't hide everything from the CYP all of their life!

- If a CYP gets upset, you have to learn to comfort them - sometimes that means leaving them to think about things on their own
- Find ways to help the CYP - anything is possible to do - find a way round things, it may take longer! Stay upbeat and positive. Talk to other people with the condition, listening to them can be helpful.

We were delighted to have Alisha, one of the CSS and Melissa, speak at one of the ASUK Global webinars to talk about growing up with Alström Syndrome and offer advice to parents/carers around the world. At the webinars, parents and carers from different countries had the chance to ask questions about how to support their own children and young people.

Their talk was called 'Don't Wrap me in Cotton Wool!' and it was so well received that they went on to do an interview style presentation at the AS Global conference. Thank you to Alisha, Melissa, Marie and all the CSS for sharing their invaluable experiences and tips.



With the aid of AS Global, more people will be able to find out about AS. The CSS are contributing to these worldwide discussions by taking part in webinars and interviews to share their lived experience. These conversations were recorded and can be found on the ASUK website.

The CSS started off as 2021 as young female group, who wanted to chat to other young women about topics affecting their lives. Over time the group have recognised that they would really welcome the input of young men who have AS, as their opinion and ideas are just as valuable as their own. From 2023, the Culture Sparkle Sisters will be changing their name to a new more inclusive title. This will mean meetings will be open to males too with AS, aged between 14 and 18 to join the group. 2023 is looking like another exciting year, where the newly named group planning to have an even louder voice!

If you would like more information about this work or find out how to take part, please get in touch with ASUK National Transition Coordinator, Marie McGee marie.mcgee@alstrom.org.uk

HUGE Congratulations to Macy for her Certificate of Achievement.
For being able to write the whole alphabet in Braille and for being able to read some letters, signs and small words.
Well done Macy!
Macy, pictured left as Mary in her recent Christmas nativity.



ASUK offer a help-line during office hours and an answer phone service at all other times where calls are promptly returned by our experienced team;

Please call 07970 071675 / 07716 135940

Email: Catherine.lewis@alstrom.org.uk

Over Christmas and New Year the office will be closed from 23rd December 22—3rd January 23



Meet the ASUK Team



Jas



Sharon



Vanessa



Richard



Alex



Toni



Kez



Trevor



Melissa



Haris



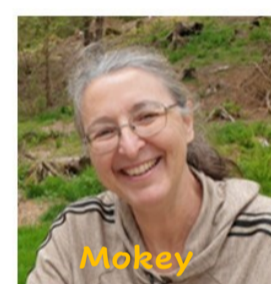
Liz



Carol



Ann



Mokey



Jane



Tim



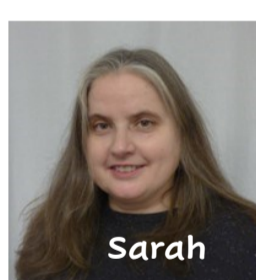
Steve



Marie



Cathy



Sarah



Kerry



Catherine



Derek



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For all enquiries please get in touch on 07970 071675 / 01709 210151

Please visit our website www.alstrom.org.uk to keep up to date with our latest news.

ASUK has a dedicated You Tube page <http://www.youtube.com/alstromsyndromeuk>

Please keep up to date with Alström Syndrome UK via twitter [@AS_UK](https://twitter.com/AS_UK) and also via our dedicated Facebook page www.facebook.com/alstromsyndromeuk please click 'like' to show your support and spread the word!

You can donate securely online, visit our Just Giving page to make a difference today, <https://www.justgiving.com/alstromsyndromeuk>

